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Participation and Activity Limitation Survey 2006: Technical and Methodological Report

2006

Social and Aboriginal Statistics Division
Jean Talon Building, 7th Floor, 170 Tunney's Pasture Driveway
Ottawa, Ontario K1A 0T6

Telephone: 613-951-5979

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The 2006 Participation and Activity Limitation Survey: Disability in Canada

Participation and Activity Limitation Survey 2006: Technical and Methodological Report

2006

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Symbols

The following standard symbols are used in Statistics Canada publications:

.	not available for any reference period
..	not available for a specific reference period
...	not applicable
0	true zero or a value rounded to zero
0^s	value rounded to 0 (zero) where there is a meaningful distinction between true zero and the value that was rounded
^{p}	preliminary
^{r}	revised
x	suppressed to meet the confidentiality requirements of the *Statistics Act*
^{E}	use with caution
F	too unreliable to be published

Contributors

Suzanne Belair, Valérie Bizier, Phyllis Chong, Julie Foucreault, Patric Fournier-Savard, Glenn Glover, Richard Hodgins, Matthew Hoffarth, Krista Kowalchuk, Jessica Legault, Mario Lisciotto, Andrew MacKenzie, Denis Malo, Joey Mousseau, Lucie Parisien, Shirin Roshanafshar, Paul Sereda, Melissa Sleightholm, Susan Stobert, Lucie Veilleux, Ziggy

Table of contents

Page

Survey description 7
Objectives 7
Background 8
Definition of disability 8
Overview of methodology 9
Target population 9
Changes to PALS target population 10
Instrument design 11
Sampling 11
Sample and stratification design 11
Sample allocation method 12
Changes to PALS sample design and sample allocation 12
Sample size 12
Data sources 12
Error detection 13
Imputation 13
Estimation 13
Quality evaluation 14
Disclosure control 14
Data accuracy 15
Severity scale 15
Data collection 16
PALS screening questions 16
Proxy and non-proxy interviews 16
Proxy rates for PALS 2006 17
Reasons for proxy 18
Collection of child questionnaire 18
Collection time frame 18
Response rates 19
Collection issues 19
Questionnaire content 21
Questionnaire content (adult) 21
Questionnaire content (child) 21
Overall content changes to PALS 21

Table of contents - concluded

Page

Content changes to adult questionnaire 23
Content changes to child questionnaire 25
The role of the Census and the linkage to PALS 26
Data dissemination 26
Appendix A: PALS 2006 severity scale for adults 27
1. Types of disability 28
2. Scores 28
3. Filter questions 30
4. Imputation of the 'undetermined' 30
5. Special cases 31
6. Construction of index 32
7. Creation of the severity classes 34
Appendix B: PALS 2006 severity scale for children 37
1. Types of disability 38
2. Scores 38
3. Filter questions 40
4. Imputation of the "undetermined" 40
5. Special cases 41
6. Construction of the global score 42
7. Creation of the severity classes 44
Appendix C: False positives in the 2006 Participation Activity Limitation Survey 47
Age groups 47
Proxy Effects 47

Participation and Activity Limitation Survey 2006: Technical and Methodological Report

Survey description

The 2006 Participation and Activity Limitation Survey (PALS) is a post-censal survey of adults and children whose everyday activities are limited because of a condition or health problem. A sample of those persons who answered "Yes" to the 2006 Census disability filter questions were chosen to participate in PALS. Approximately 39,000 adults and 9,000 children living in private, and some collective, households in the 10 provinces and 3 territories were selected to participate in the survey. PALS focuses on the relationship between functional status, daily living activities and social participation by collecting data on the nature and severity of the activity limitations, and on the needs for assistive technology, social support and accommodation in all spheres of life.

The data were collected in the fall of 2006 and winter of 2007. The survey was last conducted in 2001. This report presents some basic information about the survey and an overview of the methodological and content changes between the 2001 and 2006 PALS. The major difference involves a change in coverage resulting from the inclusion of a number of Aboriginal communities, the addition of the three territories, and the modification to the definition of collective dwellings. There are also some changes to content.

As in the Health Activity Limitations Survey (HALS 1991) and the Participation Activity Limitation Survey (PALS 2001), census information is also used in conjunction with the PALS information to provide socio-economic details on the respondents. These variables are used to aid in painting a broader picture of the people in the PALS survey.

Objectives

The objective of PALS is to develop a comprehensive database on persons with disabilities in order to:

- assist social policy development by governments of all levels
- support research in the area of disability

PALS conceptualizes disability as activity limitations and participation restrictions associated with long-term physical or mental conditions or health-related conditions.

These objectives are obtained by designing PALS to identify:

- Canadians with an activity limitation;
- the type and severity of activity limitations that they experience;
- the difficulties and barriers that they may face;
- costs incurred for assistive technology, human aids or medication due to the disability;
- the degree to which persons with disabilities are able to obtain help of physical accommodations they need at home, at work, at school or in recreational activities;
- aids and assistive technology that they need but do not have; and
- whether they have faced discrimination due to their disability.

Background

In February 1981, (The International Year of the Disabled), The Special Committee on the Disabled and Handicapped published its report entitled "Obstacles". This report made a number of recommendations to various areas of the Federal Government. One of the recommendations was for Statistics Canada to produce data on persons with disabilities in Canada using survey and program data. In order to respond to the recommendation, the government requested Statistics Canada to develop a survey on Canadians with disabilities.

In 1986, Statistics Canada conducted the first Health and Activity Limitation Survey. A second survey took place in 1991. The survey was designed to identify Canadians with disabilities and to determine what limitations they experienced and barriers they faced. In 2001, HALS was renamed as the Participation Activity and Limitations Survey (PALS). The PALS survey program builds on the groundwork laid by the 1986 and 1991 HALS. As with HALS, PALS is a joint effort by Human Resources Development Canada (HRSDC) and Statistics Canada.

PALS data is used by disability and social policy analysts at all levels of government, as well as by associations for persons with disabilities and researchers working in the field of disability policy and programs. The federal, provincial and territorial governments released their common disability framework in 1998, calling for the promotion of greater inclusion of persons with disabilities in all aspects of Canadian society. Their 1998 report noted the importance of developing a reliable statistical database on disability and underlined the key role PALS would play in supporting policy development and research in this area.

Governments use the PALS data to plan programs and services for persons with disabilities in their jurisdictions and to predict likely rates of program take-up based on different eligibility criteria. Personal outcome indicators in the areas of education, employment and income are also key data requirements for the development and evaluation of their social, disability and income-support policies. Comparisons of these outcome indicators for persons with and without disabilities form an important aspect of policy analysis undertaken at the federal, provincial and territorial levels.

Definition of disability

Disability is an activity limitation or participation restriction associated with a physical or mental condition or health problem.

PALS uses the World Health Organization's (WHO) framework of disability provided by the International Classification of Functioning (ICF). This framework defines disability as the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors.

The ICF is a multi-dimensional classification, encompassing both a medical and a social model of disability. The ICF is intended to have a number of applications as a statistical tool, a research tool, a clinical tool, a social policy tool, and as an educational tool.

For the purpose of PALS, persons with disabilities are those who reported difficulties with daily living activities, or who indicated that a physical or mental condition, or health problem reduced the kind or amount of activities they could do. The respondents' answers to the disability questions represent their perception of the situation and are therefore subjective.

Overview of methodology

Target population

The PALS target population consists of all persons, adults and children, who have an activity limitation or a participation restriction associated with a physical or mental condition or health problem and who were living in Canada at the time of the Census.

This population included persons living in private and some collective households in the 10 provinces and the three territories. However, for operational reasons, the populations living on First Nations reserves, the residents of institutional and some non-institutional collectives were excluded. More precisely, the non-institutional collective dwellings excluded were military bases, Canadian Armed Forces vessels, merchant vessels and coast guard vessels, as well as campgrounds and parks.

In order for PALS to reach its target population, all persons who reported "yes" to either of the two disability filter questions on the 2006 Census of Population questionnaire were included in the survey frame. The Census filter questions are as follows:

1. Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
   1. Yes, sometimes
   2. Yes, often
   3. No

2a. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at home?

   1. Yes, sometimes
   2. Yes, often
   3. No

2b. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at work or at school?

   1. Yes, sometimes
   2. Yes, often
   3. No

2c. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do in other activities, for example, transportation or leisure?

   1. Yes, sometimes
   2. Yes, often
   3. No

From this frame, a sample of individuals was selected for the PALS interview. The subset of the surveyed population that also reports disabilities in PALS is considered as the target population. In other words, according to PALS, a person with a disability is defined as a respondent who answers:

YES to a disability filter questions on Census, **and**

YES to disability filter questions in PALS, **or**

YES to detailed questions on activity limitations in PALS

Changes to PALS target population

The target population in 2006 differed slightly from that in 2001. In 2006, the territories were included in the target population. In addition, in 2001, the population living in Aboriginal communities was covered by the Aboriginal Peoples Survey (APS) and was thus excluded from the 2001 PALS target population. In 2006, these Aboriginal communities were included in the PALS target population.

Furthermore, the method of collecting information in the senior citizen residences that are non-institutional collective dwellings was modified slightly in the 2006 Census. Prior to this, people living in these residences received only short forms for the Census. Since then, modifications to this process have been made and now one in five households in these senior residences receives a Census long form; a rate comparable to regular private dwellings. Consequently, these collective dwellings are now included as part of the PALS target population.

It should be noted that since comparisons between 2001 PALS and 2006 PALS results were a key objective in 2006, Statistics Canada derived a historic variable based on the 2001 target population. PALS users will now have the option to directly compare results between 2001 and 2006 but also study the new 2006 target population.

In total, these changes in the target population represent an increase of 1.2% in the number of people included in PALS 2006 (see Table 1). This increase differs slightly from one province to another due to the addition of the Aboriginal communities and the concentration of Aboriginal Peoples in some provinces.

Table 1

People covered by the 2006 Participation and Activity Limitation Survey and percentage increase resulting from the changes between the two populations by province

Province	Population covered in 2006	Population covered in 2006 and in scope in 2001	Percentage of increase in the covered population
	number		percent
Newfoundland	86,940	84,590	2.7
Prince Edward Island	25,620	25,410	0.8
Nova Scotia	206,980	206,220	0.4
New Brunswick	144,050	143,960	0.1
Quebec	945,800	936,890	0.9
Ontario	2,288,940	2,276,020	0.6
Manitoba	215,430	211,620	1.8
Saskatchewan	179,930	167,170	7.1
Alberta	565,780	555,910	1.7
British Columbia	854,880	852,820	0.2
Yukon	4,980	0	100.0
Northwest Territories	4,360	0	100.0
Nunavut	2,640	0	100.0
Canada	**5,526,320**	**5,460,600**	**1.2**

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006, rounded data.

Instrument design

Many different stakeholders were consulted during the development of the adult and children questionnaires for the 2006 PALS. A review of the questionnaires from both the 2001 PALS and the 1991 Health and Activity Limitation Survey (HALS) were conducted. Furthermore, consultation with the client HRSDC, federal and provincial governments and community associations were also held to obtain input for the 2006 survey.

Along with these consultations, several rounds of qualitative testing were conducted in order to test the content of the two questionnaires. This testing took place between 2004 and 2006. Additionally, a pilot test, in both official languages, was conducted in the spring of 2006. This allowed PALS staff to make final changes to the survey content as well as test different aspects of the data collection.

Sampling

Sample and stratification design

The sample design used for PALS 2006 was a two-phase stratified design based on the 2006 Census. In Phase 1, the census itself, the long form was systematically distributed to approximately every fifth household across Canada. Phase 2 involved the selection of individuals who reported an activity limitation during Phase 1 based on various characteristics defining the strata.

The strata were defined in order to ensure large enough samples in the domain estimates and to optimize the sample allocation. Therefore, since one of the survey objectives was to allow for statistical profile dissemination of individuals with a disability by province/territory and of various age groups in the population, these domain estimates were considered in the development of the strata. For the provinces, the domain estimates considered were made through the intersection of the province and the following age groups:

- younger than 15 years old
- 15 to 24 years old
- 25 to 44 years old
- 45 to 64 years old
- 65 to 74 years old
- 75 years and over

The domain estimates for children and adults in the territories were made differently. The estimates for the children were obtained by combining the three territories whereas the estimates for the adults were obtained by separating the three territories.

Furthermore, for a more optimal sample allocation, the severity of the respondent's disability was also included as a stratification variable. Individuals who are severely limited answered "yes, often" at least once to the filter questions in the Census. Mildly limited individuals answered "yes, sometimes" at least once to the filter questions in the Census but never answered "yes, often." The final variable considered in the construction of the strata was probability of selection in Phase 1. Including this variable in the stratification therefore made it possible to minimize the variability of the initial weight of individuals selected in the same domain and therefore optimizing the sample allocation.

Sample allocation method

Sample distribution was performed in a way that, for each domain, a minimum proportion is guaranteed with a maximum coefficient of variation (CV) of 16.5%. At Statistics Canada, 16.5% corresponds to the upper limit of a CV in order to be able to effectively qualify the corresponding estimate. Among children aged 0 to 14 years, the minimum proportion to estimate was set to 8%. Among young adults (15 to 24), this proportion was set to 9%. Among adults aged 25 to 44 years and 45 to 64 years, this proportion was set to 7.5%. Finally, the proportion was set to 11% for adults aged 65 to 74 years and 75 years and older.

Changes to PALS sample design and sample allocation

The sample design used for the 2006 PALS differed slightly from the 2001 PALS. Due to improvements in the processing of Census data, 2006 data was available in electronic format earlier than it was in 2001. This earlier access made it possible to directly select PALS 2006 respondents from the Census database. This was an advantage that was not available during the 2001 survey. In 2001, respondents were selected directly from the questionnaire boxes making it necessary for the design and allocation to reflect this constraint.

The 2001 PALS sample design was a two-stage stratified sample. At the first stage, Census enumeration area (EA) was selected using probability proportional to size sampling. The second stage involved the selection of individuals according to their characteristics (stratum formed by the province and the age group). It is clear that the efficiency of the 2006 PALS sample design exceeds that of the 2001 PALS allowing for a superior geographic distribution and allocation of the sample.

Nevertheless, it is important to point out that despite the changes made to the PALS sample design and allocation, the comparability of the two surveys is not affected. In fact, the only impact of these changes affects the probability of the selection of each individual in PALS and therefore, the respondents' weight. When using weighted estimates, the changes made have no impact on the results of the survey.

Sample size

The total size of the PALS 2006 sample was 47,793: 8,954 children (persons under 15 years of age) and 38,839 adults (15 years of age and over). In 2001, 43,276 individuals were selected for PALS. The increase in the 2006 PALS sample size will facilitate the in-depth analysis of issues concerning people with disabilities in the territories and provinces.

Data sources

PALS data collection took place between October 30 2006 and February 28 2007. The interviews were conducted by telephone with the interviewers completing a computer-assisted questionnaire. Because of the numerous advantages it offers, PALS was conducted for the first time by computer assisted interviewing (CAI). It has been shown through other surveys that Computer assisted telephone interview (CATI) improves accuracy of data collected in telephone surveys. It allows interviewers to more easily follow the path in complex questionnaires by taking the interviewers to the next appropriate question based on answers provided by the respondents. Furthermore, the answers given by the respondents are directly captured during the interview making them available electronically immediately. In addition, procedures of quality control can be incorporated directly into the application.

For the adult interviews, the respondent targeted was the selected person and for the child interviews, it was the parent or guardian of the child. However, proxy interviews were allowed in those situations where an adult respondent was unable to answer the questions over the telephone. Further details surrounding the issue of proxy interviews are provided in the following section.

Error detection

The first phase of error detection was carried out during data collection. Edit rules were incorporated in the CATI system to ensure that data capture errors and inconsistencies were reduced. Secondly, the interviewing supervisors observed interviews and reviewed the completed questionnaires in order to identify inconsistencies. Any inconsistencies were discussed with the interviewer who had conducted the interview and the respondents were called back if required.

The second phase of error detection was conducted during data processing and is referred to as the editing phase. Edit rules were developed to validate that respondents followed the right path in the questionnaires and to identify and correct inconsistencies between responses within each section of the questionnaires. For the majority of cases with inconsistencies, an automated correction was specified. This is discussed in greater detail in the Imputation Section. Once this step was completed, a macro verification was conducted by analyzing frequency distributions to identify anomalies such as missing categories or unusually large frequencies.

Imputation

For PALS, a valid response was deterministically imputed for the missing responses if sufficient information was available in the related questions. Otherwise, it was coded to "Not asked". In addition, the questions that were not to be asked were coded to "Valid skip". If a question with a missing answer (coded to "Not asked") should have been used to determine if subsequent questions were to be asked, these subsequent questions were set to "Not stated", because it was not possible to determine whether the question should have been asked.

A non-response is not permitted for demographic information that is required for weighting. The information on age and sex of the respondent is important for later data analysis. In addition, this information assisted in the verification that the correct person had been reached for the interview. These two variables were imputed from the census if the data was missing or invalid. In particular, an age was considered invalid if it was not consistent with the questionnaire that had been administered.

Estimation

In a sample survey, each respondent represents not only himself or herself, but also other people that were not sampled. Thus, a weight is assigned to each respondent creating a representative for a number of people. In order to maintain consistency, this weight must be used for all estimations.

The weight is calculated in a three-stage process. The FIRST stage involves the assignment of an initial weight based on the sampling design. The initial weight is the inverse of the inclusion probability. For the 2006 PALS, the initial weight is the product of two components: the census weight and the subsampling weight (the inverse of the sampling fraction in the second phase). Following this calculation, appropriate weight adjustments are applied.

The SECOND stage of the weighting process includes the adjustment for non-response. More specifically, two adjustments are made at this point. It should be noted that non-respondents can be classified into one of two main categories with very different characteristics: the people not contacted and the people contacted but who did not respond.

The weights are adjusted first for non-contact and then for non-response. As the adjustment method is the same for both types of non-respondents, it is described here only for non-response. The non-response adjustment is done by forming non-response adjustment classes in such a way that the records in each class have similar response probabilities. The estimated response probabilities are obtained by developing a logistic regression model to predict the response probability using explanatory variables.

Many explanatory variables can be used in order to model the probability of response. Given that PALS is a post-censal survey, all long form Census information is available for each respondent and non-respondent. Furthermore, other important variables to predict response are available. Such data collection information as the number of attempts to contact a household, and the time and day of the attempts can be used as well. Separate models are used for children and adults. Different classes are then created based on response probabilities and a minimum number of respondents by class. The inverse of the weighted response rate in a class is used as the weighting adjustment factor. The initial weights of the respondents within the class are adjusted accordingly.

The THIRD stage of the weighting adjustment is the post-stratification. This adjustment ensures that the sum of the final weights for the respondents is equal to the population counts obtained from the census. This adjustment is made for groups (post-strata) defined by the combinations of different variables for which this adjustment is important. Examples include province, sex, age group and severity of the limitation reported in the census. The weights corrected for non-response are then adjusted using the ratio of the census count to the sample count for each post-stratum.

Since estimates are obtained from a sample as opposed to a census, estimates will vary from sample to sample referred to as sampling error. The bootstrap method is used to provide estimates of sampling error for statistics with PALS data. This resampling method selects 1,000 subsamples (with replacement) from the main sample. Each subsample is then weighted by calculating the initial weights and applying the same adjustments applied to the main sample weights, i.e. adjustments for non-response and post-stratification. The sampling error is measured and estimated by the bootstrap variance which is the empirical variance of the desired statistic calculated from the main sample and the 1,000 bootstrap subsamples.

Quality evaluation

There are two types of error that occur in surveys; sampling and non-sampling errors. Unlike sampling errors, non-sampling errors are not explained by sample-to-sample variability and can not be quantified. These errors may occur at any step of the survey process. The various measures outlined below were adopted to minimize these errors in PALS 2006.

As mentioned previously, a pilot test was conducted seven months before the survey. During this test, all survey processes were evaluated, from the questionnaire content and the computer assisted questionnaire to the data processing method.

High response rates are essential for quality data. To reduce the number of non-response cases, the interviewers were provided training by experienced Statistics Canada training staff. In conjunction with the training, detailed interviewer manuals were provided as a reference. Furthermore, all of the interviewers were under the direction of interviewer supervisors. When the need arose, refusals were followed up by senior interviewers to encourage respondents to participate in the survey.

In addition, measures were taken in order to identify and correct errors that could result from misinterpretation of a question by the respondent or a wrong flow in the questionnaire. The questionnaires were first reviewed by the interviewer supervisor. A detailed set of edit rules were then used during data processing to identify and correct any inconsistencies between the responses provided. These edit rules were exhaustively tested before being applied to the data.

Disclosure control

Statistics Canada is prohibited by law from releasing any data that would divulge information obtained under the Statistics Act that relates to any identifiable person, business or organization without the prior knowledge or the consent in writing of that person, business or organization. Various confidentiality rules are applied to all data that are released or published to prevent the publication or disclosure of any

information deemed confidential. If necessary, data are suppressed to prevent direct or residual disclosure of identifiable data.

Data accuracy

The data accuracy measure used for each table produced is the estimated standard error of the estimate (sampling error measure), which is the square root of the estimated sampling variance of the estimate. However, the estimated standard error is usually expressed relative to the estimate to which it pertains, and the resulting measure is the estimated coefficient of variation (CV).

The estimated CV is obtained by dividing the estimated standard error of the estimate by the estimate itself and is expressed as a percentage of the estimate. For PALS, all estimated CVs will be obtained using the bootstrap method described in the ESTIMATION Section.

At Statistics Canada, we quantify the accuracy of an estimate by the CV. A small CV implies a small variability in the sample and, consequently, better quality of the estimate. PALS uses the following measurements:

(i) When the CV is greater than 33.3%, the estimate is considered "unacceptable";

(ii) When the CV is greater than 16.5% and less than or equal to 33.3%, the estimate is considered "poor" and must be used with caution;

(iii) When the CV is 16.5% or less, the estimate is considered "acceptable" and can be use without any restrictions.

The ideal case would be to produce estimates with an associated CV of 16.5 or less.

Severity scale

A disability severity index was developed using questions for each type of disability in the PALS questionnaires. At first, a standardized score for each type of disability was calculated based on severity, the maximum score given for someone who reports being completely disabled for a given disability. Questions on intensity and frequency of the limitation were used in order to determine the severity of the disability. For example, a maximum score was given in a situation where someone reported being completely unable to take part in an activity because of a disability and this difficulty was always present.

Next, an overall score of severity was calculated taking the average of all standardized severity scores calculated for each type of disability. Due to the strong relationship between learning difficulties and developmental disability, only the score given to the developmental disability was taken into account in the overall score for respondents reporting both disabilities.

Finally, after discussion with data users, it was decided that the severity scale should be divided into four severity classes. These were created by examining the distribution of the global severity score. In the first step, an attempt was made to identify a "natural cut-off" point in the scale. This cut-off point corresponds to the 70^{th} percentile and is close to a score of 1/9 for the adults and 1/8 for the children. Since these particular scores correspond to the score of someone with a maximum score for one type of disability, it was decided to subdivide the scale into two parts. The two groups were then subdivided again into two parts consisting of four other classes. These two new cut-off points are equivalent to half and twice the maximum score obtained for one disability.

These classes are defined as:

Class 1: Respondents with a score equivalent to less than half the maximum score for one disability.

Class 2: Respondents with an equivalent score between half and the maximum score for one disability.

Class 3: Respondents with an equivalent score between one and twice the maximum score for one disability.

Class 4: Respondents with a score equivalent to more than twice the maximum score for one disability.

In light of the relatively subjective nature of this classification and in order to avoid any misinterpretation, it is preferable not to use specific terms to characterize the classes. The interpretation of the measurement tool is as follows: persons in Class 4 have a more severe disability than persons in Class 3, who in turn have a more severe disability than persons in Class 2, and so forth. However, for practical purposes, names of "mild," "moderate," "severe" and "very severe" were assigned to the classes 1 through 4. It should be noted that there is no judgment associated with the use of this terminology.

Because questions differ according to a child's age, two different scales were created, one for children aged 0 to 4 and another for children aged 5 to 14. Taking into account there are only 4 types of disabilities measured for children aged 0 to 4, only two severity classes were created. The first was labelled as "mild to moderate" and the second was labelled "severe to very severe".

Further technical details regarding how severity scales were derived can be found in appendix A and B.

Data collection

PALS screening questions

The PALS interview begins with a disability identification module: the two disability filter questions and a series of detailed questions on activity limitations. The interview continues with follow-up questions related to the limitation if this identification module reveals the presence of a disability. This identification happens through a positive answer to at least one question. If a positive answer is not given, the respondent is streamed to the false positive module where they are asked questions to assist in determining why they had reported positively to a filter question on the census but no longer report an activity limitation on PALS.

The PALS screening questions ask the respondent about individual types of limitations such as, vision, hearing, mobility, agility, pain, memory, learning, developmental and emotional or psychological conditions. For those who trigger a limitation, questions are asked about the main condition.

Proxy and non-proxy interviews

When an interview is conducted with the actual respondent, the interview is considered to be a "non-proxy" interview. However, in some situations, there may be the need for someone to answer the survey on behalf of the respondent. In these cases, the interview is considered to be a "proxy" interview.

In the adult questionnaire for PALS 2006, every effort was made to contact the respondent directly. If the respondent was not available when the interviewer called, follow up attempts were made. When proxy interviews were required, someone else such as a spouse, parent, child or care giver responded on their behalf.

In the PALS 2006 child questionnaire, the respondent targeted to participate in the survey on behalf of the child under the age of 15 was a parent or guardian. In other words, an interview is considered as being a non-proxy interview when the parent or the guardian of the child answers the survey. However, in some cases, this person was not available and the interview was administered to another household member or someone else. In those cases, the interview was considered to be a proxy interview.

A proxy is selected when:

- The respondent is absent for the duration of the survey.
- The respondent cannot speak English or French.
- The respondent cannot participate due to a physical or mental condition.
- A parent wants to respond for his or her 15 to 18-year-old child.

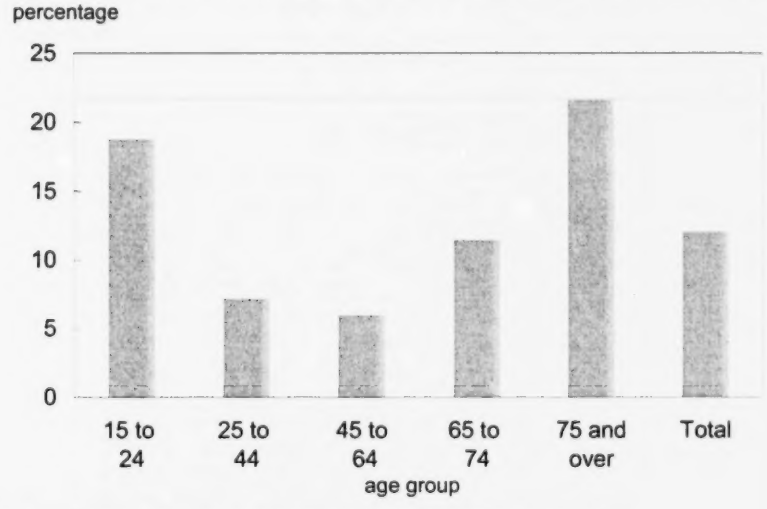
People who are serving as a proxy in an interview need to meet the following requirements:

- Be an adult who can speak either English or French.
- Be available to be contacted during the collection of the survey.
- Be one of the most knowledgeable persons regarding the difficulties and challenges the person faces as a result of their activity and participation limitations.
- When a person starts as the proxy in an interview, that same person has to finish it. The proxy can not switch half way through the interview.

In many cases the proxy lives in the same household and may be related to the individual. However, it is possible that the proxy may be an older sibling, guardian, parent, grandparent, adult child or a home care/ health care provider who does not live in the same household. In circumstances such as this, the person who is able to provide the best data quality would be used as the proxy.

Proxy rates for PALS 2006

Chart 1
Proxy response rates by age, Participation and Activity Limitation Survey, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

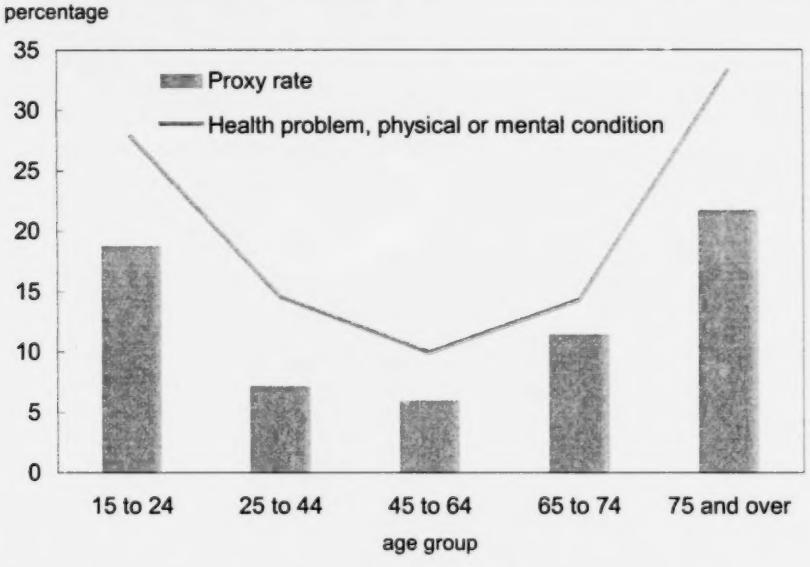
Overall, the proxy rate among those aged 15 and above was 12.1%. Among adolescents and adults, the bulk of proxy respondents consisted of parents, spouses and partners, and adult children.

As Chart 2 illustrates, proxy respondents in the high proxy rate age groups were more likely to report health problems, physical conditions or mental conditions as the reason for why a proxy was necessary. Consequently, the proxy rates follow a bowl-shaped pattern with the youngest age group, 15 to 24 year olds, and oldest age group, those over 75 years of age, relying on proxies most frequently. For the former group, parents were much more likely to answer on behalf of their adolescent children whereas for the oldest age group, adult children were most likely to answer on behalf of their elderly parents.

Reasons for proxy

The most cited reason among respondents age 15 and above for using a proxy was the presence of a health problem, physical condition, or mental condition. Nearly 60% of proxy respondents were unable to complete the survey themselves for this reason. The existence of a language barrier was the next most common issue, affecting 14.8% of proxy respondents. A similar proportion of adolescent proxy respondents (under the age of 18) and dependent adults had their parents choose to answer the survey on their behalf (9.4% and 8.3% respectively).

Chart 2
Proxy rate and proportion of proxy respondents citing health problems or physical or mental conditions as the reason for proxy, by age, Participation and Activity Limitation Survey, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Collection of child questionnaire

The Child Questionnaire is used to interview the parents or guardians of children who were under 15 years of age on May 16, 2006. All child interviews are usually completed by a parent or guardian of the child. If the parent or guardian is unable to complete the questionnaire for any reason, a proxy can take their place, otherwise the interview ends The child is never asked to answer the survey.

Collection time frame

The original collection period was October 30, 2006 to January 31, 2007 but an extension for collection was granted to February 28, 2007. This extension resulted in a 3.9% increase in the response rate for the Adult Survey and a 4.9% increase for the Child Survey.

Response rates

The response rate for the children at the end of collection was 79.7%. The response rate for the adults was slightly lower at 73.9%. When combining the two rates, the overall response rate for the PALS 2006 was 74.9%. The following tables provide the response rates by province and different age groups.

Table 2
Distribution of the sample and response rates by age, Participation and Activity Limitation Survey, 2006

Age groups	Sample size	Response rate
	number	percent
Children aged 0 to 14	**8,954**	**79.7**
0 to 4	1,890	79.2
5 to 9	3,121	80.1
10 to 14	3,943	79.7
Adults aged 15 and over	**38,839**	**73.9**
15 to 19	4,164	79.0
20 to 24	4,213	69.2
25 to 34	3,528	70.0
35 to 44	6,136	72.4
45 to 54	4,427	76.6
55 to 64	4,763	78.0
65 to 74	5,768	77.0
75 to 84	4,142	72.4
85 and over	1,698	60.2
Total	**47,793**	**74.9**

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006, rounded data.

As shown in Table 2, it was more difficult to obtain an answer from younger adults aged 20 to 34 and older people aged 85 and over. This is a trend that is consistent with other social surveys.

Collection issues

There are always challenges when conducting interviews for a survey as large scale as PALS. In the 2006 collection, there were issues concerning tracing. There were a number of cases that were difficult to trace or were not traceable at all. The number of these cases was relatively high for the PALS 2006. Tracing respondents is quite demanding in terms of resources and time. For post-censal surveys like PALS, there is a dependency on the accuracy of contact information provided on the Census forms.

PALS also encountered some unique collection challenges in the territories. Many households do not have telephones and a number of respondents speak only Aboriginal languages. Because of this, many interviews had to be transferred to other regional offices where more interviewers were able to speak Aboriginal languages. This transferring of cases assisted in the successful completion of a number of such interviews.

Table 3
Distribution of the sample and response rates by province and type of questionnaire, Participation and Activity Limitation Survey, 2006

Provinces and type of PALS questionnaire	Sample size	Response rate
	number	percent
Total - Newfoundland and Labrador	**4,096**	**78.9**
Children	741	85.1
Adults	3,355	77.5
Total - Prince Edward Island	**2,804**	**75.8**
Children	239	86.9
Adults	2,565	74.7
Total - Nova Scotia	**4,375**	**79.1**
Children	850	83.5
Adults	3,525	78.0
Total - New Brunswick	**4,547**	**73.4**
Children	850	80.4
Adults	3,697	71.8
Total - Quebec	**4,865**	**79.4**
Children	998	84.6
Adults	3,867	78.0
Total - Ontario	**5,096**	**73.3**
Children	964	75.8
Adults	4,132	72.8
Total - Manitoba	**4,708**	**72.9**
Children	864	75.0
Adults	3,844	72.4
Total - Saskatchewan	**4,493**	**75.5**
Children	881	79.4
Adults	3,612	74.6
Total - Alberta	**4,581**	**73.8**
Children	862	79.5
Adults	3,719	72.4
Total - British Columbia	**4,865**	**72.9**
Children	1,005	79.8
Adults	3,860	71.1
Total - Yukon	**1,021**	**70.9**
Children	110	78.1
Adults	911	70.1
Total - Northwest Territories	**1,136**	**73.1**
Children	185	75.3
Adults	951	72.6
Total - Nunavut	**1,206**	**62.9**
Children	405	67.3
Adults	801	60.7

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Questionnaire content

Questionnaire content (adult)

The PALS questionnaire collects information on various aspects of the individual's every day life. Information gathered about these respondents assists the development of policies to further the quality of life for those who have an activity limitation or disability. Some of the different subject areas of questioning include:

- Type of disability and severity
- Aids and assistive devices
- Employment history and training
- Education characteristics
- Main condition and cause
- Care needed and received
- Local and long distance transportation
- Housing needs and modifications
- Internet use
- Social participation
- *Plus* household information from the census

Questionnaire content (child)

Similar to the adult questionnaire, the child specific questionnaire collects information on the child. In this situation, the parents of the children are asked to respond to the questions. There are also questions that ask the parents about their impressions of how their lives are impacted by having a child with a limitation or disability.

The two questionnaires are separated because the issues and concerns surrounding adults and children when dealing with disability and limitation differ depending on age and circumstance. However, there are many modules of questions that are asked for both the adults and the children. Examples of this are the census filter questions and the PALS screening questions.

For the child questionnaire, the following information is collected:

- Type of disability and severity
- Aids and assistive devices
- Main condition
- Help received and needed
- Diagnosis
- Child care – type and satisfaction
- Education – special education, unmet needs, transportation
- Leisure and recreation
- Home accommodations
- Impact on the family
- *Plus* household information from the census

Overall content changes to PALS

There have been some noteworthy modifications to both the child and adult questionnaires for the 2006 PALS. Throughout the content development process for the 2006 survey, it became clear through research and discussions with the advisory group that there was a need for additional information

surrounding disability issues. Many of the already existing sections were enhanced by the addition of new questions focusing on specific issues not already explored.

A. Internet use

Access to information is a common barrier faced by persons with a disability or limitation. With the advancement in the areas of adaptive technology, internet use has become more user friendly to persons with activity limitations. Computer and the internet can impact both the access to information and leisure aspects of life for those with a disability.

In conjunction with the idea of access to information, the internet can also be used as a method to take part in training. This is an extremely viable solution for people who have difficulty in mobility and navigation. The internet can provide the same types of training courses as could be found in colleges and universities without the obstacle of mobility.

Taking into account the number of areas the internet could be used to aid a person with a disability, a line of questioning was recommended by the PALS advisory group. These modifications were suggested for both the child and adult questionnaire for PALS 2006 in order to establish the impact the internet has on the daily lives of Canadians with activity limitations and the level of importance such technology has become in their day to day lives.

B. Health utility index (HUI)

The Health Utility Index was another line of questioning that is new to PALS 2006 in both the child and adult questionnaires. This is a quantitative health measurement that fits nicely into the framework of PALS.

The HUI collects health status information on topics such as hearing, sight, speech and overall mental well-being. It is a generic health status index that is able to synthesize both quantitative and qualitative aspects of health. The index, developed at McMaster University's Centre for Health Economics and Policy Analysis, is based on the Comprehensive Health Status Measurement System (CHSMS). It provides a description of an individual's overall functional health, based on eight attributes: vision, hearing, speech, mobility (ability to get around), dexterity (use of hands and fingers), cognition (memory and thinking), emotion (feelings), and pain and discomfort.

The scores of the HUI embody the views of society concerning health status. Each person's preferences are represented as a numerical value. This index is also used by the National Population Health Survey.

The HUI has the robustness to provide a reliable quantitative measure for health. It was added to coincide with the more general questions pertaining to the respondent's health. Furthermore, it allows comparison of PALS to other surveys that also use the HUI. Finally, it serves as a tool of validation of the PALS filter questions.

C. False positive module

This was a new module for PALS 2006 for both the children and adults. A false positive occurs when a person indicates in one of the filter questions on the census form that he/she or someone in their household has a limitation and then reports on PALS that they do not. This line of questioning was added because PALS 2001 experienced approximately a 25% false positive rate between the Census and PALS. The false positive module inquires about the reasons a person reported a limitation on the Census but not on PALS. Understanding these reasons allows refinement of the sample design and sheds light on potential improvements for the future.

There are several different reasons for how false positives occur. It could be an issue of proxy when a person indicates a limitation on the Census but the actual respondent does not see themselves as having a limitation or disability. It may also be as simple as the person reading the question not fully understanding what it is asking. The majority of false positives were people recovering from injuries, illnesses or surgery at the time of the Census and who were no longer limited at the time that PALS took place.

Because this is a very important issue for PALS, a number of qualitative studies investigating the reasons for false positives took place in early 2007 shortly after collection ended. An analysis of the results from these qualitative studies has taken place. A full analysis of the false positive rate from PALS 2006 will take place in the upcoming months. Further information concerning false-positives from PALS 2006 can be found later in this document.

D. Care received and needed by the respondent

The modules concerning every day activities shifted focus slightly in order to gather more detailed information from the caregiver perspective. This was accomplished mainly by ensuring the modules themselves were "activity" specific and "caregiver" specific. By relating these two dimensions, a more clear and detailed picture is presented.

E. Aids and devices

As mentioned earlier, having proper access to technology is essential when having an activity limitation or disability. The requirement and maintenance of aids and assistive devices was an area to explore in PALS 2006. Additional content on this topic was added to the existing 2001 PALS material to examine the frequency of use of aids, payment of costs, service required, capacity to pay for service, replacement cycles, and capacity to pay for replacement.

In many cases, adaptive technology makes it possible for a person with a disability to accomplish daily tasks and take part in leisure activities. Establishing the costs and longevity of assistive equipment is essential in order to ensure policies are put in place to make certain that equipment is accessible to those who need it.

F. Housing

The housing module received some minor content additions to provide information on the sources of funding for housing modifications and payment arrangements, activities that may be limited by the design and/or layout of the home, and the impact of these limitations.

Consultations with researchers and stakeholders highlight the importance of understanding the dynamics involved in housing modifications for people with activity limitations. If proper modifications are not in place, it can make it virtually impossible for a person with an activity limitation to move throughout or function within their own environment.

Content changes to adult questionnaire

A. Work related training – experience and barriers

The work-related training portion of PALS was significantly enhanced to provide more detail on the amount and types of training available to people with activity limitations. Of particular interest were any barriers to training they may face, use of new skills and reasons for taking workplace training.

The advisory committee suggested increasing the workplace training content to better understand the dynamics of workplace training for people with activity limitations. The idea of work place training is

not always the easiest task for an employee with a disability. In many situations, there are numerous barriers to receiving training for employees with activity limitations due to lack of accessible materials and trainer sensitivity.

B. Short and long distance travel

Research has indicated that manoeuvring around the environment can be a major challenge for those who have a disability or limitation. It was suggested by the advisory committee to expand the line of questioning on both short and long distance travel for PALS 2006.

Public transit is not always accessible to those with varying disabilities or limitations. Improvements are slowly taking place and accessibility is increasing, but this is an aspect of life for a person with an activity limitation that can have a major effect on movement around their environment and therefore has an impact upon their level of independence.

Additional questions on local travel can aid in providing detailed information on how people who are limited or disabled move around their environment. There are many different methods by which short distance travel can be done but in order to assist future programs and ensure continued advancements, it is essential to understand the issues preventing travel.

Information on long distance travel is just as vital as short distance travel. There are many obstacles that a traveler with a disability can face when attempting to take an air plane, train or bus. For example, the presence of a wheel chair or service animal can cause a significant difficulty for the person. As with short distance travel, it is crucial to understand a respondent's travel experiences, as well as the types of barriers they face.

These questions give the respondent the opportunity to express the type and frequency of the difficulties he/she may experience on a regular basis and which mode of transportation poses the greatest challenge and the reasons for the challenge.

C. Employment

The employment section of the PALS 2006 survey has undergone the greatest number of changes. PALS 2006 more clearly separates people who have retired from a job or business versus people who were not successful in the labour market and have stopped looking for work.

A drawback in the 2001 survey concerns the method by which the respondents were flowed to questions in the employment section. The 2001 PALS did not differentiate between people who had retired from a job or business verses those who had stopped looking for work but had indicated on PALS 2001 they were retired. The dynamics of these two groups are dramatically different and it was essential that these groups be differentiated in the 2006 survey.

There are many different issues facing these two very diverse groups of people. Those who are able to work but can not find work due to their limitation have a story quite different from those who are retiring. Often there is the desire to work but for different reasons: that is, they are unable to obtain employment. It is these barriers to employment that are vital to identify in order to find solutions.

Similarly, those facing the challenges of going through retirement with the presence of an activity limitation or disability will have a differing viewpoint on the experience from someone without a difficulty. In order to take this into account, additional content was added to the retirement module to examine the factors related to the decision to retire and the role that the condition may have played in the decision.

Previous research has illustrated the complexity of the retirement decision and how this decision can be further complicated by the presence of an activity limitation. It is on this basis that a decision to define these two groups differently was made.

Content changes to child questionnaire

As well as making some improvements to existing questions, PALS 2006 has also been updated with the addition of entirely new questions. This new content has been included to ensure that any gaps in information present in the previous PALS are not left unexamined in 2006.

A. Impact on the family of having a child with a disability

A line of questioning concerning the impact on the family having a child with a disability or limitation was new in 2006. Research has demonstrated that having a child with a disability can impact the family in many different ways and on many different levels.

The impact on a family of a child with a disability is multidimensional. In some cases one or both parents will leave their employment in order to stay at home with the child. This can lead to enormous financial burden on the family as well as family stress.

B. Experience and barriers in child care

The topic of childcare is at the forefront for many young Canadian families in our society today. Finding a suitable childcare arrangement for most families can be a difficult task when the child does not need any special accommodations. The process of finding appropriate childcare arrangements for children requiring special accommodations may be even more challenging.

Often it is difficult for a family to find a childcare provider who is able to offer the type of care required for a child with a limitation. Facilities may not offer the modifications to the environment needed to accommodate a child with severe physical disabilities. The childcare providers may not have the skills required to provide proper care. An example of this may include a deaf child who uses sign language to communicate.

Cost is always another important issue that needs to be explored. If children with activity limitations require a specialized childcare arrangement due to their limitation, it is important to understand the cost implications for the family. There are specific questions in the PALS 2006 that collect information on many realms of the childcare experience that will assist in providing a clearer overall picture.

C. Special education programs

Since 2001, there has been a significant growth in the integrated school system. Segregation is not as common in 2006 as it had been only 5 years ago. In many cases, the child with an activity limitation or disability can receive adapted courses and proper accommodations in a local school as opposed to having to travel far distances to attend a segregated school.

It was necessary for PALS to change the questionnaire in 2006 to reflect these types of changes to specialized education. Questions have been rephrased to be applicable to both children attending an integrated or a segregated school.

The role of the Census and the linkage to PALS

PALS respondents are advised at the time of collection that information they provide to the survey will be added to information already provided to the 2006 Census. Adding Census data to the PALS master file will allow the addition of information on the respondent's socio-economic and household characteristics. Furthermore, a No sample will be available that will allow comparison between persons who are disabled and non-disabled.

Data dissemination

The dissemination of the PALS survey will be in stages from December 2007 to September 2008. Because the household variables are taken from the census, PALS can not release this data until the census has released the equivalent variables.

The first release in December 2007 will provide disability rates for both children and adults. The May 2008 Release of data from PALS 2006 will include data concerning care, aids and assistive devices and impact on the family. Following the May release, the July 2008 Release will present data on education and employment. Finally, the last release in September 2008 will include income and housing data.

It is planned that each release will focus where possible on change from 2001 to 2006. Furthermore, also included will be a package of relevant tables by province, age, sex, type of disability and severity. Finally, it is intended to package these tables at the end to create profiles of disability by type of disability and by province.

Appendix A: PALS 2006 severity scale for adults

Table of contents

Page

1. Types of disability 28
2. Scores 28
3. Filter questions 30
4. Imputation of the 'undetermined' 30
5. Special cases 31
6. Construction of index 32

An index for measuring the severity of disability was constructed on the basis of responses to the screening questions for the 2001 PALS. This index was calculated also for the 2006 PALS in order to compare results of both surveys. This document presents the methodology used to construct the adult disability index.

1. Types of disability

To construct the index, ten types of disabilities were considered: hearing, seeing, communication, mobility, agility, pain and discomfort, learning difficulties, memory problems, developmental disability and psychological conditions.

Points are assigned to each question on the basis of severity. For some types of disability, more than one question is asked. Each of these questions seeks to measure a functional limitation related to the disability. Thus, for example, to measure hearing-related disability, three questions are asked:

(1) How much difficulty do you have hearing what is said in a conversation with one other person?
(2) How much difficulty do you have hearing what is said in a conversation with at least three other persons?
(3) How much difficulty do you have hearing what is said in a telephone conversation?

A score is thus derived for each of these questions. Further on, we will see how these scores are then combined to obtain a single score per type of disability. Table 4 below shows the number of functional limitations measured by the PALS questionnaire by type of disability as well as the contexts for which these questions are asked.

Table 4
Number of functional limitations and contexts by type of disability

Type of disability	Variable names	Functional limitations	Contexts
(A) Hearing	HEAR	3	General
(B) Seeing	SEE	2	General
(C) Communication	COMM	2	Family, friends, services and other
(D) Mobility	MOBI	5	General
(E) Agility	AGIL	7	General
(F) Pain and discomfort	PAIN	1	Home, work, school and other
(G) Learning	LEAR	1	Home, work, school and other
(H) Memory	MEMO	1	Home, work, school and other
(I) Developmental	DEVE	1	Home, work, school and other
(J) Psychological	PSYC	1	Home, work, school and other

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

2. Scores

Some questions measure the intensity of the disability, while others instead measure the frequency of its presence. Both types of questions are used in calculating scores. Points are assigned to each question on the basis of severity. Thus, when there is no disability, no points are assigned. Conversely, the maximum score is given for total disability. For example, for an intensity question, scores are assigned as follows:

- "Some difficulty": 1 point
- "A lot of difficulty": 2 points

- "Completely unable": 3 points
- Other answer (no, refusal, don't know): 0 points

For a frequency question, points are assigned as follows:

- "Yes, sometimes": 1 point
- "Yes, often or always": 2 points
- Other answer (no, refusal, don't know): 0 points

When both intensity and frequency are available for a given type of disability, the product of the scores for the two questions is used.

For each type of disability, a single value is required. Take, for example, the case of hearing, for which three different questions are asked: "How much difficulty do you have hearing what is said in a conversation with one other person?" (HEAR1), "How much difficulty do you have hearing what is said in a conversation with at least three other persons?"(HEAR2) and "How much difficulty do you have hearing what is said in a telephone conversation?" (HEAR3). Here the three scores must be combined in order to have only one score. The same is true for questions asked in different contexts: these sub-questions must be combined to have only one score for each type of disability. For example, for learning difficulties, the same question is asked for four contexts: home, work, school and other.

Since the number of questions varies depending on the disability, we standardized the indices by type of disability, so as not to over-represent types for which there are numerous questions. We do not want to assign more weight to one type of disability than to another. Where there is more than one question for a given type, the scores for these questions are summed and the sum is then standardized to obtain a score that lies between 0 and 1:

$$S_T = \left(\frac{1}{\sum_{i=1}^{N} M_{T_i}} \right) \sum_{i=1}^{N} S_{T_i} \qquad \text{(1a)}$$

Where S_T is the score for disability type T, N is the number of different questions (functional limitations) for type T, M_{T_i} is the maximum score for the i^{th} question for disability type T and S_{T_i} is the score obtained for the i^{th} question for disability type T. In some cases, S_{T_i} may be made up of more than one question. When the same question is asked in different contexts, we take the mean of the scores for each of the contexts. For example, for learning difficulties, since the same question is asked four times, we take the mean of the four scores:

$$S_{T_i} = \frac{1}{C_{T_i}} \sum_{j=1}^{C_{T_i}} S_{T_{ij}} \qquad \text{(2a)}$$

Where C_{T_i} is the number of different contexts in which the i^{th} question of disability type *T* is asked and $S_{T_{ij}}$ is the score for question *i* and context *j* of type *T*.

The following is an example for communication-related disability (*T*=COMM). This type of disability is made up of two different questions ($N = 2$), COMM1 (*difficulty speaking*) and COMM2 (*difficulty making yourself understood*). COMM1 is asked in a general context ($C_{T_1} = 1$), whereas COMM2 is asked in four different contexts (*family, friends, professional services, and other*) ($C_{T_2} = 4$). The maximum value of COMM1 is 3, while the maximum value of COMM2 is 2 ($M_{T_1} = 3$, $M_{T_2} = 2$):

$$COMM = \frac{1}{(3+2)}(COMM_1 + COMM_2) \tag{1b}$$

Where $COMM_1$ is asked in a general context and where:

$$COMM_2 = \frac{1}{4}(COMM_{2\ family} + COMM_{2\ friends} + COMM_{2\ services} + COMM_{2\ other}) \tag{2b}$$

3. Filter questions

For respondents who have a non-nil index value based on the screening questions, no additional points are assigned for answers to the filter questions. But for respondents who have no points based on the screening questions *(that is, basically the "yes-no's", YES at the filter questions and NO to the screening questions*), points are assigned on the basis of the four filter questions. The overall score for the filter questions is calculated in the same way as for the types of disability, based on the expressions (1a) and (2a). In this case, we have $N = 2$, $M_{T_1} = M_{T_2} = 2$, $C_{T_1} = 1$ and $C_{T_2} = 3$.

4. Imputation of the 'undetermined'

For some respondents, we have enough information to know that they have a certain type of disability but the information for them is incomplete because either intensity, frequency or both are missing. They were initially assigned an "undetermined" flag and a score of 0, with the intention of imputing them after a score was calculated for all those for which the information was complete.

For imputation, we decided to confine ourselves to a relatively simple technique. It consists in looking for a group of respondents having the same responses to certain questions as the respondent to be imputed and imputing the mean of their scores. Here is an example:

A respondent has answered "Yes, sometimes" to Question AMOF_Q02 (difficulty walking), but he has not answered Question AMOF_Q03 on the intensity of the disability. Among all the respondents for whom the information is complete for these two questions, we look for those who have the same response to

Question AMOF_Q02. We then take the mean of the scores for this disability and impute this value to the "undetermined" respondent.

This type of action is justified by the fact that there is a correlation between the frequency question and the intensity question. A person who answers "Yes, often or always" to the frequency question is more likely to answer "Completely unable" or "A lot of difficulty" to the intensity question than persons who answered "Yes, sometimes" to the frequency question.

Imputation specific to PALS 2006

Because of a change in the flow of the questions in PALS 2006, a component of the severity indicators associated with mobility was imputed for some respondents to ensure that the severity indicators for 2001 and 2006 remained comparable. In 2001, respondents who stated that they were unable to walk still had to answer the question AMOF_Q09 pertaining to the difficulties of moving from one room to another. In 2006, this question's placement was modified so that those who stated they were incapable of walking did not respond to this question. All the same, since this question was part of the calculation of the severity indicators for these people in 2001, it was therefore decided that a score would be imputed for this question in 2006. To do this, the average score obtained for 2001 was used. 688 adults were affected in the total by this rule.

5. Special cases

There are some types of disability for which we ask,

A) Whether a given condition reduces the quantity or number of activities that a respondent can engage in (frequency question).

If the answer is yes, we then ask,

B) How many activities does this condition prevent (at home, at work, at school, elsewhere).

A respondent is considered limited if he/she answers "Yes" to A). However, the respondent may answer "None" to each of the four contexts in question B). This situation is not corrected by the rules during processing. Since the points on the scale are assigned on the basis of the combined response to A) and B) (generally the product of the two), no points are assigned to persons in this situation (since B=0), even though they are considered as being limited for the type of disability concerned. Thus, overall, a respondent may be limited for two types of disability but have points for only one type or even, in some cases, for neither type.

We decided to assign a minimum number of points to these respondents for the types of disability for which this problem arises. Accordingly, we assign one point to everyone who answered "Yes" to A), and then we calculate the score for B) as presented above. For example, if the maximum score for a given type of disability is 6 (frequency (2) X intensity (3)), then with this change, the maximum score becomes 7 and respondents who have a "Yes" for A) and "None" for B) have a score of 1. To summarize,

"Yes" to A) and "None" to each question in B):	1 point
"Yes" to A) and at least one answer to B):	1 point + points assigned to B)

In this way, respondents who answered "None" throughout B) will necessarily have the lowest score, since they have points only because of A).

For some types of disability, a respondent is considered limited (and is assigned points accordingly) if a disability is reported even though there is no limitation. In such cases (learning difficulty and

developmental disability), a point is still assigned even if the answer to the frequency question is negative. These special cases, along with the questions for which an additional point is assigned for a "Yes," are shown in Table 5, below.

Table 5
Special cases

Type of disability	Variable	Question for which a point is assigned for a "yes"
Communication	COMM2	ACFT_Q02 or ACFT_Q05
Pain and discomfort	PAIN	APFT_Q03
Learning	LEAR	ALFT_Q01 or ALFT_Q02
Memory	MEMO	AMFT_Q02
Developmental	DEVE	ADFT_Q01
Psychological	PSYC	AEFT_Q02

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

6. Construction of index

We observed an important relationship between learning difficulties and developmental disability. For a majority of persons with developmental disability, a learning difficulty was also reported. We therefore decided that when points are assigned to a respondent for a developmental disability, points cannot also be assigned for learning difficulties.

The overall score is calculated taking the average of all standardized scores. Unlike what was done in the case of children, where the presence of two age groups not having the same questions requires that two scales be calculated, the score for adults is calculated in the same way for respondents of all ages:

$$SI = \frac{1}{9}\left(\begin{matrix} S_{HEAR} + S_{SEE} + S_{COMM} + S_{MOBI} + S_{AGIL} + S_{PAIN} + \\ I_{DEVE}\, S_{LEAR} + S_{MEMO} + S_{DEVE} + S_{PSYC} \end{matrix}\right) \qquad (3)$$

Where $I_{DEVE} = \begin{cases} 0 & if \quad S_{DEVE} \neq 0 \\ 1 & if \quad S_{DEVE} = 0 \end{cases}$

This scale is derived for people who have an affirmative answer to the screening questions (the "yes-yes" group and the "no-yes" group) only. For the "yes-no" group, only the filter questions are used to calculate the score, and these questions are considered to represent an additional disability:

$$SI_{YN} = \frac{1}{10} S_{FILT} \qquad (4)$$

The reason why we did not consider the filter questions in (3) is that it is not desirable to have redundant information. For example, a person who has a disability related to mobility has probably answered "Yes" to the filter questions, thinking of his/her mobility-related disability (the filter questions being general in nature) and also answered "Yes" to the mobility questions.

For the "yes-no" group, the reason why they did not answer "Yes" to the screening questions is probably that we are unable to measure their type of disability with our questionnaire or that they had too mild a

disability to be reported in the screening questions. For this reason, we dealt with them separately and assigned a relatively low score.

A few results concerning the overall index are shown in Tables 6 and 7. First, Table 6 presents descriptive statistics according to the number of disabilities reported. Thus, for a given number of disabilities, it shows the number of respondents having that number of disabilities, the mean and the standard deviation from the overall index for these respondents, as well as the minimum and maximum values. As may be seen, the mean increases with the number of disabilities, which is entirely desirable. The same is true for the standard deviation. When the number of disabilities is large, there may be people who have several mild disabilities and other that are quite severe, and who have a high score for a number of disabilities.

Table 6

Descriptive statistics by number of disabilities (unweighted data)

Disability	Frequency	Percentage	Mean	Minimum	Maximum	Standard deviation
			number			
No disability	6,119	-21.4	0.00000	0.0000	0.00000	0.00000
One disability	4,170	-14.6	0.02570	0.0027	0.11111	0.01868
Filters only	794	-2.8	0.03000	0.0083	0.10000	0.01812
Two disabilities	4,053	-14.2	0.05285	0.0064	0.22222	0.03254
Three disabilities	6,027	-21.0	0.09717	0.0187	0.30741	0.05130
Four disabilities	3,873	-13.5	0.14912	0.0346	0.42130	0.06940
Five disabilities	1,968	-6.9	0.20373	0.0568	0.52963	0.08722
Six disabilities	935	-3.3	0.27030	0.0884	0.66667	0.10767
Seven disabilities	467	-1.6	0.33827	0.0937	0.74259	0.12400
Eight disabilities	195	-0.7	0.40458	0.1845	0.81129	0.13486
Nine disabilities	31	-0.1	0.47370	0.2547	0.77738	0.13953
Total	**28,362**	...	...	...	...	...

... not applicable

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Table 7 shows, by number of disabilities, the proportion of respondents having each of the disabilities identified. Thus, row 1 of the table shows that among persons with one disability, 22.5% have a disability related to hearing, 5.9% a disability related to seeing, 1.2% to communication, etc. As may be seen, disabilities such as PAIN, HEAR and MOBI are often unaccompanied by other disabilities (30.8%, 22.5% and 14.5% respectively). Also, MOBI, AGIL and PAIN are often present together, since the rates are similar in each row starting with row 2.

Other approaches were considered in order to limit the redundancy of the information contained in the severity scale. In addition to the strong relationship between developmental disability and learning disability, there are other significant correlations between some disability types in the scale. For example, there is a strong correlation between mobility difficulties, agility difficulties and pain and discomfort. Thus, in many cases, a person who has mobility problems also has some pain and discomfort. On the other hand, seeing or hearing difficulties are more often encountered on their own.

In order to remove redundancy of information, an unequally weighted scale was considered. Instead of having a weight of 1, disability types that are strongly correlated would have a smaller weight in the global score. Since it is difficult to justify the use of unequal weights in the scale, this option was rejected.

Table 7

Frequency of different types of disability by number of disabilities (weighted data)

Disability	HEAR	SEE	COMM	MOBI	AGIL	PAIN	LEAR	MEMO	DEVE	PSYC
						percentage				
One disability	22.5	5.9	1.2	14.5	8.7	30.8	10.7	0.5	1.7	3.7
Two disabilities	21.5	9.6	7.8	45.9	37.1	53.2	11.3	2.5	3.7	7.3
Three disabilities	17.2	8.9	7.3	82.1	80.4	80.9	8.2	4.1	3.9	6.9
Four disabilities	40.2	26.0	17.0	88.0	87.5	85.3	15.8	12.3	8.1	19.9
Five disabilities	48.2	42.6	32.8	92.0	91.6	87.5	28.0	31.4	13.7	32.1
Six disabilities	43.2	46.4	56.6	94.3	93.2	92.5	43.4	61.6	20.3	48.4
Seven disabilities	49.7	56.7	74.7	98.3	97.4	94.6	53.1	79.7	29.6	66.2
Eight disabilities	74.4	79.0	90.3	99.5	99.5	97.4	67.7	93.3	22.6	76.4
Nine disabilities	100.0	100.0	100.0	100.0	100.0	100.0	74.2	100.0	25.8	100.0

Note: See Table 4 for description of variable name.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

7. Creation of classes

In order to create severity classes, the distribution of the global severity score was examined. The distribution has been separated into deciles. The first decile corresponds to the 10% of people with activity limitation with the lowest scores. The second decile corresponds to the next 10% of people with activity limitation with the lowest scores, etc. The average score was calculated for each decile and a plot of this average score as a function of the decile was produced in Chart 3.

As can be seen in Chart 3, no obvious cut-off points in the global severity score distribution exist. Several techniques were considered in order to create the severity classes. However, given the continuous nature of the severity curve and because it was desirable to employ a strategy that users would readily understand, we were unable to enter into exhaustive analyses, and we had to confine ourselves to a relatively intuitive approach. Thus, the severity classes were essentially determined by means of a graphic analysis of the data.

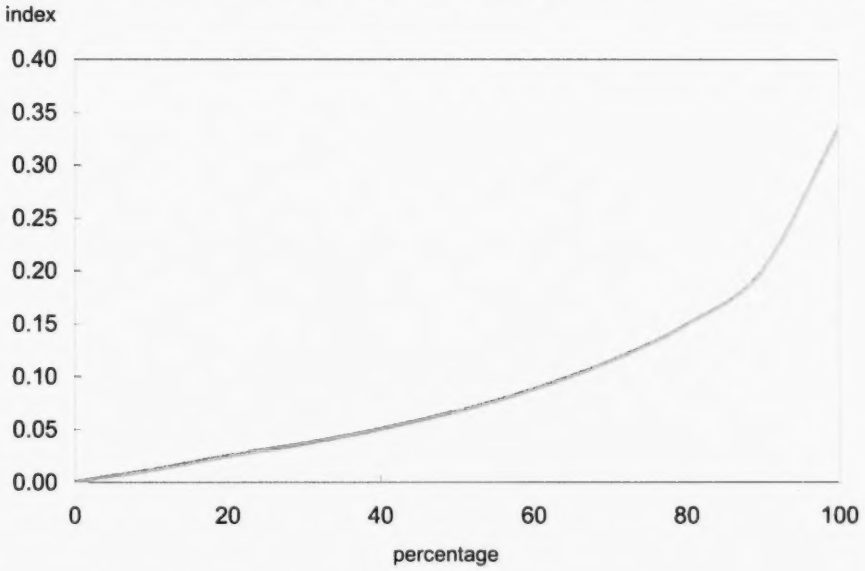
After discussion with some data users, it was decided that the severity scale should be cut into four severity classes, Class #1 being the less severe and Class #4 the most severe. The creation of the classes has been done in two steps.

In a first step, an attempt was made to identify a "natural cut-off point" in the scale. Although this is not obvious, one can note that the beginning of the distribution is fairly linear up to 70th percentile and then, the slope starts to increase more and more rapidly. This cut-off point in the trend of the distribution seems to correspond to a score around 1/9. This particular score corresponds to the score of someone with the maximum score for one type of disability and no points for the other types. Many such cases were found in the sample. Of course, there is a number of ways to obtain a score of 1/9. Because of the particular interpretation of this point, the cut-off was chosen to be exactly 1/9. This cut-off creates two groups:

"Least severe" $SI < 1/9$

"Most severe" $1/9 \leq SI \leq 1$

Chart 3
Distribution of the global score for adults, Participation and Activity Limitation Survey, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

For example, a person with a total disability related to seeing ($S_{VUE} = 1$), but with no other disability, would fall into the most severe group. Table 8 shows the number of persons in this situation as well as the types of disability concerned. It also shows the number of persons who have more than one disability with a maximum score and no points for other disabilities. Thus, there are only 37 cases where there is a score of 1 for a one disability and where the nine other types are nil. Problems of seeing (18 cases) and pain and discomfort (13 cases) are the severe disabilities most often unaccompanied by others.

Table 8
Number of cases for which the maximum score was assigned for a given number of disabilities and a nil score for all others (unweighted data)

Number of disabilities	Frequency	HEAR	SEE	COMM	MOBI	AGIL	PAIN	LEAR	MEMO	DEVE	PSYC
						number					
1	62	11	22	1	1	...	17	1	...	2	7
2	4	...	...	1	...	...	1	1	1	3	1
3	4	...	1	1	2	2	2	...	1	2	1
4	2	...	...	2	2	2	...	1	...	1	...
6	1	...	...	...	1	1	1	1	1	...	1

... not applicable
Note: See Table 4 for description of variable name.
Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

We then separated these two groups into two parts. These two boundaries correspond to respectively half and double the maximum score obtained for a given disability. Thus, respondents who have a score lower than half the maximum score for a disability are included in Class 1, while those who have a score that lies between half the maximum score for a disability and the maximum score for that disability are in Class 2. Those whose score lies between the maximum score for a disability and double that score are in Class 3, while those with a score greater than double the maximum score for a disability are in Class 4:

Class 1			*SI*	<	1/18
Class 2	1/18	≤	*SI*	<	1/9
Class 3	1/9	≤	*SI*	<	2/9
Class 4	2/9	≤	*SI*	≤	1

The advantage of this classification system is that it is easy for all users to understand and interpret. In light of the subjective nature of such a system, we preferred not to use specific terms to characterize the classes, so as to avoid misinterpretations. The only possible interpretation of these classes is that according to our measurement tool, persons in Class 4 have a more severe disability than persons in Class 3, who in turn have a more severe disability than persons in Class 2, and so forth. However, for practical purposes, these classes were assigned names. We use the terms "mild," "moderate," "severe" and "very severe" to designate classes 1 to 4 in that order. It should be noted that there is no judgment associated with the use of this terminology; the classes of severity depend on the way in which the scale is constructed.

Appendix B: PALS 2006 severity scale for children

Table of contents

Page

1. Types of disability 38
2. Scores 38
3. Filter questions 40
4. Imputation of the "undetermined" 40
5. Special cases 41
6. Construction of the global score 42
7. Creation of the severity classes 44

For PALS 2001, an index measuring the severity of the disability has been constructed based on answers to the filter and screening questions. This index was recalculated for PALS 2006 in order to compare results of both surveys. The methodology used to produce the severity scale for children is presented in this paper. Please note that the interviews about children activity limitation were conducted with the parent or guardian of the child.

1. Types of disability

For children as for adults, there are 10 different types of disability: hearing, seeing, speech, mobility, dexterity, learning, delay, developmental disability, psychological condition and chronic health condition. Table 9 below presents the different disability types and the age group(s) for which each type applies. This table also presents the different contexts in which disability questions are asked. It should be noted that only one functional limitation is measured for each disability type except for speech where two functional limitations are measured.

Table 9
Type of disability for children

Types of disability	Age 0 to 4 years	Age 5 to 14 years	Context
(A) Hearing	HEAR	HEAR	General
(B) Seeing	SEE	SEE	General
(C) Speech	...	SPEE	Family, friends and other
(D) Mobility	...	MOBI	General
(E) Dexterity	...	DEXT	General
(F) Learning	...	LEAR	Home, school and play
(G) Delay	DELA	...	General
(H) Developmental disability	...	DEVE	Home, school and play
(I) Psychological condition	...	PSYC	Home, school and play
(J) Chronic health condition	HEAL	...	Home, school and play

... not applicable

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

For adults, since the same questions were asked for all age groups, a single scale was derived and applied to all respondents. For children however, two different scales were constructed because some questions differ according to the age of the child. Two scales were constructed, therefore, one for the 0 to 4 years old and one for the 5 to 14 years old.

2. Scores

Some questions measure the intensity of the disability while others the frequency of the disability. Both types of questions are used in the calculation of the scores. Scores are assigned for each question in increasing order of severity. For example, the points given for a question measuring the intensity are as follows:

- "Some difficulty": 1 point
- "A lot of difficulty": 2 points
- "Completely unable": 3 points
- Other answer (Refusal, Don't know, No difficulty): 0 points

For frequency questions, the points are distributed similarly:

- "Yes, sometimes": 1 point
- "Yes, often or always": 2 points
- Other answer (No, Refusal, Don't know): 0 points

When both frequency and intensity are available, the product of the two scores is used. For each disability type, a unique score is required. For speech disability, two different questions are asked: the ability to speak and the ability to make himself/herself understood. These two questions (two scores) have to be combined in order to obtain a unique score for this type of disability. Furthermore, for certain disability types, the same question is asked in different contexts. For example, for learning disability, Question CLFT_Q04 is asked for both the home and school situation as well as for play or recreational activities. These sub-questions also have to be combined in order to obtain a unique score for a given disability type.

When there is more than one question for a particular type, the scores are added and then standardized in order to obtain a score between 0 and 1:

$$S_T = \left(\frac{1}{\sum_{i=1}^{N} M_{T_i}} \right) \sum_{i=1}^{N} S_{T_i} \qquad (1a)$$

Where S_T is the score for disability type *T*, N is the number of different questions for type *T*, M_{T_i} is the maximum score for the i^{th} question of type *T* and S_{T_i} is the score obtained for the i^{th} question of type of *T*. In some cases, S_{T_i} could be made up of more than one question. When the same question is asked in different contexts, the mean of the scores is calculated. For example, for speech disability, Question COFT_Q05 about the ability of the child to make himself/herself understood, is asked in three contexts: when speaking with family members, friends or other people. Since the same question is asked three times, the mean score is assigned to this type:

$$S_{T_i} = \frac{1}{C_{T_i}} \sum_{j=1}^{C_{T_i}} S_{T_{ij}} \qquad (2a)$$

where C_{T_i} is the number of different contexts in which the i^{th} question of disability type *T* is asked and $S_{T_{ij}}$ is the score for question *i* and context *j* of type *T*.

Here is an example for speech disability (*T*=SPEE). This type is composed of two different questions ($N = 2$), SPEE1 (*difficulty speaking*) and SPEE2 (*difficulty to make himself understood when speaking*). SPEE1 is asked in a general context ($C_{T_1} = 1$) while SPEE2 is asked in three different contexts (*family*,

friends and other) ($C_{T_2} = 3$). The maximum score for SPEE1 is 3 and the maximum score for SPEE2 is 2 ($M_{T_1} = 3$, $M_{T_2} = 2$):

$$SPEE = \frac{1}{(3+2)}(SPEE_1 + SPEE_2) \qquad (1b)$$

where $SPEE_1$ is asked for a unique context and where:

$$SPEE_2 = \frac{1}{3}(SPEE_{2\ family} + SPEE_{2\ friends} + SPEE_{2\ other}) \qquad (2b)$$

The mean score of Question COFT_Q05 over the three contexts is calculated in expression (2b), while in expression (1b), the score for SPEE is standardized in order to obtain a score between 0 and 1.

3. Filter questions

For respondents with a score different than zero for the screening questions, no additional points are assigned for the filter questions. However, for respondents with no points for the screening questions, essentially the "yes-no" group (*YES to the filter questions and NO to the screening questions*), points are given based on the four filter questions. A global score for filter questions is computed the same way than the score attributed to each disability type, with expression (1a) and (2a). In this case, $N = 2$, $M_{T_1} = M_{T_2} = 2$, $C_{T_1} = 1$, $C_{T_2} = 3$.

4. Imputation of the "undetermined"

For children for whom enough information is available to determine that they have activity limitations, but the intensity and/or the frequency are unavailable, a flag of "Undetermined" is assigned and their score for that specific disability type is imputed. A fairly simple method was used for the imputation. This technique consists of looking for a group of respondents with the same answers to specific questions as the respondent with incomplete information. The average score of this group of respondents is then imputed for the respondent with the missing information. Here is an example:

A respondent has an answer of "Yes, sometimes" to Question CMFT_Q01 about mobility disability, but there is no answer to CMFT_Q02 on the intensity of the disability. All respondents who gave the same answer as this respondent to CMFT_Q01 are obtained, then the average score for mobility is calculated and this value is imputed for the "Undetermined" respondent.

This method of imputation is justified by the fact that there is a correlation between the frequency and the intensity. People answering "Yes, often" to the frequency question are more likely to answer "Completely unable" or "A lot of difficulty" than people answering "Yes, sometimes".

5. Special cases

There are certain disability types for which the following is asked:

A) *If the condition reduces the amount or the kind of activity the respondent can do* (the frequency question).

And then, if the answer is "Yes":

B) *How many activities does this condition usually prevent the respondent from doing (at home, at school, at play or recreational activities).*

A respondent is considered limited if he/she answered "Yes" to A. However, it is possible to answer "None" to all four contexts in Question B. This situation is not changed by the edit rules that are used for both the adult and the child questionnaire. Since the points are assigned based on the product of the score to Question A and the score to Question B, no point is assigned in this case (score to B = 0). However, the respondent is considered limited for that specific disability type. For example, a respondent can be limited globally for four disability types, but points could be assigned for less than four types (for example, two types). In particular, a respondent could be considered limited with no point at all.

It was decided to assign a minimal score to these people for the specific disability type. This was done by giving one point to all people who answered "Yes" to A, and then by calculating the score as originally planned based on Question B. For example, if the maximum score for a given disability type is six (frequency (2) X intensity (3)), this maximum score now becomes seven with this modification. Respondents with " Yes " to A and "None" to B would obtain a score of 1. In summary:

"Yes" to A and "None" to each question of B: 1 point

"Yes" to A and at least one answer to B: 1 point + points given for B

Respondents with the answer "None" to B will therefore necessarily be the ones with the smallest score as they will only have the point for A.

For some disability types, a respondent is considered limited (and points are assigned) if a disability is reported, even if there is no limitation. So, in these cases, points are always assigned. This is the case for learning disability and developmental disability. The list of these particular disability types and the questions where an additional point is given for a "Yes" are presented in Table 10.

Table 10
Special cases

Type of disability	Variables	Questions for whom an additional point is given for a "Yes"
Speech	SPEE2	COFT_Q02 or COFT_Q04
Learning	LEAR	CLFT_Q01 or CLFT_Q02
Developmental disability	DEVE	CDFT_Q03
Psychological condition	PSYC	CEFT_Q02
Chronic health condition	HEAL	CHRC_Q02

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

6. Construction of the global score

There is a strong relation between learning disability and developmental disability. For most of the respondents reporting a developmental disability, a learning disability is also declared. However, from a subject-matter point of view, it could be argued that these two disability types are exclusive. In order to avoid double counting of points, respondents with a developmental disability are not given any additional points for reporting a learning disability.

The global score is computed by taking the mean over all the standardized scores of each disability type. As mentioned earlier, two different scales were derived for children, one for the 0 to 4 years old and one for the 5 to 14 years old:

$$SI_{0-4} = \frac{1}{4}(S_{HEAR} + S_{SEE} + S_{DELA} + S_{HEAL}) \qquad (3a)$$

$$SI_{5-14} = \frac{1}{8}\left(\begin{array}{l} S_{HEAR} + S_{SEE} + S_{SPEE} + S_{MOBI} + S_{DEXT} + \\ I_{DEVE}\, S_{LEAR} + S_{DEVE} + S_{PSYC} + S_{HEAL} \end{array} \right) \qquad (3b)$$

where

$$I_{DEVE} = \begin{cases} 0 & if\ S_{DEVE} \neq 0 \\ 1 & if\ S_{DEVE} = 0 \end{cases}$$

These two scales are computed only for those with a positive answer to the screening questions (the "yes-yes" group and the "no-yes" group). For the "yes-no" group ("Yes" to the filter questions but "No" to the screening questions), only the filter questions are taken into account and this group forms an additional type of disability (unknown):

$$SI_{YN,0-4} = \frac{1}{5} FILT \qquad (4a)$$

$$SI_{YN,5-14} = \frac{1}{9} FILT \qquad (4b)$$

The reason why we did not use the filter questions also in (3a) and (3b) was to avoid double counting of the same information. For example, a child with a mobility disability probably answered "Yes" to the filter questions thinking about his/her mobility limitation and answered "Yes" also to the mobility questions.

Individuals in the "yes-no" group probably answered "No" to the screening questions because the PALS questionnaire could not measure their disability or simply because they are too mildly disabled to report a positive answer to the screening questions. This is the reason why this group was treated separately. A very small disability score was given to that group.

Some results for the global score are presented in Table 11 and Table 12 below. Table 11 (Table 11a for children 0 to 4 and Table 11b for children 5 to14) shows the number of children with one to four disabilities and the number of children with no disability or with points coming only from the filter questions. For each group, the mean, the minimum value, the maximum value and the standard deviation of the global score are presented. For example, there are 13 respondents aged between 0 to 4 with four disabilities (the maximum value for this age group). The mean score is 0.65137 with a standard deviation (STD) of 0.17398, a minimum value of 0.34524 and a maximum value of 0.91667.

Table 11a

Number of disabilities and statistics - children aged 0 to 4

Disability	Frequency	Percentage	Mean	Minimum	Maximum	Standard deviation
			number			
No disability	847	-57.2	0.00000	0.0000	0.00000	0.00000
Filters only	44	-3.0	0.07689	0.0167	0.20000	0.04271
One disability	257	-17.4	0.11193	0.0357	0.25000	0.06160
Two disabilities	254	-17.2	0.29187	0.1191	0.50000	0.09785
Three disabilities	66	-4.5	0.47788	0.2441	0.75000	0.13946
Four disabilities	13	-0.9	0.65137	0.3452	0.91667	0.17398
Total	**1,481**	...	...	...	...	...

... not applicable

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Table 11b

Number of disabilities and statistics - children aged 5 to 14

Disability	Frequency	Percentage	Mean	Minimum	Maximum	Standard deviation
			number			
No disability	1,684	-30.1	0.00000	0.0000	0.00000	0.00000
Filters only	1,008	-18.0	0.03620	0.0179	0.12500	0.01931
One disability	180	-3.2	0.04007	0.0093	0.11111	0.02164
Two disabilities	783	-14.0	0.08180	0.0357	0.25000	0.03759
Three disabilities	736	-13.2	0.14067	0.0566	0.37500	0.05689
Four disabilities	669	-12.0	0.22688	0.0804	0.50000	0.08650
Five disabilities	347	-6.2	0.32331	0.1121	0.62500	0.11752
Six disabilities	141	-2.5	0.44160	0.1895	0.75000	0.15439
Seven disabilities	36	-0.6	0.51777	0.2669	0.87500	0.17272
Eight disabilities	7	-0.1	0.63945	0.3522	0.96226	0.19823
Total	**5,591**	...	...	...	...	...

... not applicable

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

The proportion of children with a certain type of disability by number of disabilities is presented in Table 12. As for Table 11, results are presented separately for the 0 to 4 children (Table 11a) and for the 5 to 14 children (Table 11b).

Other approaches were considered in order to limit the redundancy of the information contained in the severity scale. In addition to the strong relationship between developmental disability and learning disability, there are other significant correlations between some disability types in the scale. In order to remove redundancy of information, an unequally weighted scale was considered. Instead of having a

weight of 1, disability types that are strongly correlated would have a smaller weight in the global score. Since it is difficult to justify the use of unequal weights in the scale, this option was rejected.

Table 12a

Frequencies for each type - children aged 0 to 4

Disability	HEAR	SEE	DELA	HEAL
		percentage		
One disability	10.1	3.5	37.4	49.0
Two disabilities	8.3	7.9	94.1	89.8
Three disabilities	51.5	50.0	100.0	98.5
Four disabilities	100.0	100.0	100.0	100.0

Note: See Table 9 for description of variable name.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Table 12b

Frequencies for each type - children aged 5 to 14

Disability	HEAR	SEE	SPEE	MOBI	DEXT	LEAR	DELA	DEVE	PSYC	HEAL
						percentage				
One disability	9.4	6.2	6.6	1.7	0.8	26.9	3.2	1.5	43.8	9.4
Two disabilities	16.3	8.2	29.2	11.4	6.1	51.1	13.3	9.3	55.0	16.3
Three disabilities	11.0	5.7	52.0	12.0	13.3	50.1	39.1	38.2	78.5	11.0
Four disabilities	13.9	9.9	81.2	12.9	27.7	35.3	60.4	67.9	91.0	13.9
Five disabilities	22.2	15.3	94.5	25.4	74.9	24.5	74.1	73.5	95.7	22.2
Six disabilities	26.2	56.0	94.3	70.9	89.4	22.7	75.9	66.0	98.6	26.2
Seven disabilities	58.3	77.8	97.2	83.3	91.7	13.9	83.3	97.2	97.2	58.3
Eight disabilities	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

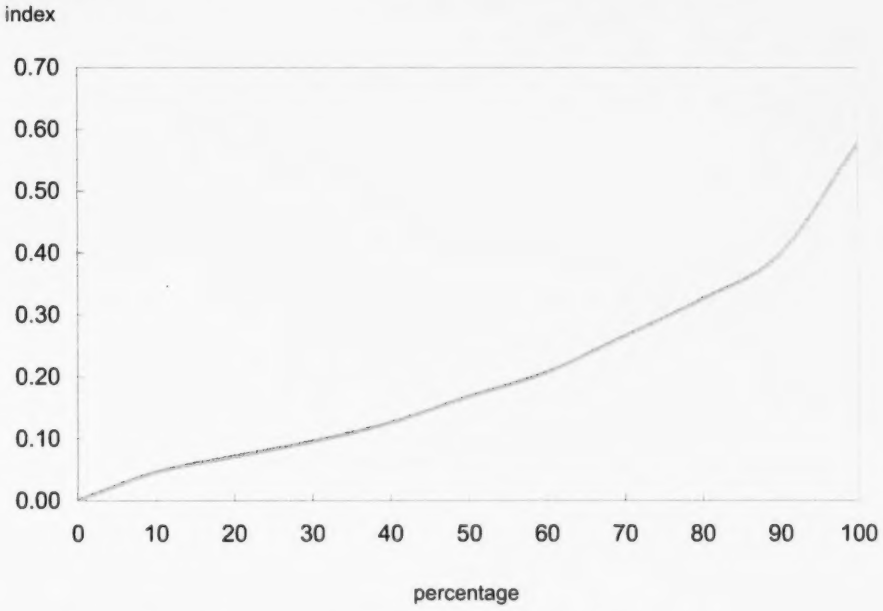
Note: See Table 9 for description of variable name.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

7. Creation of the severity classes

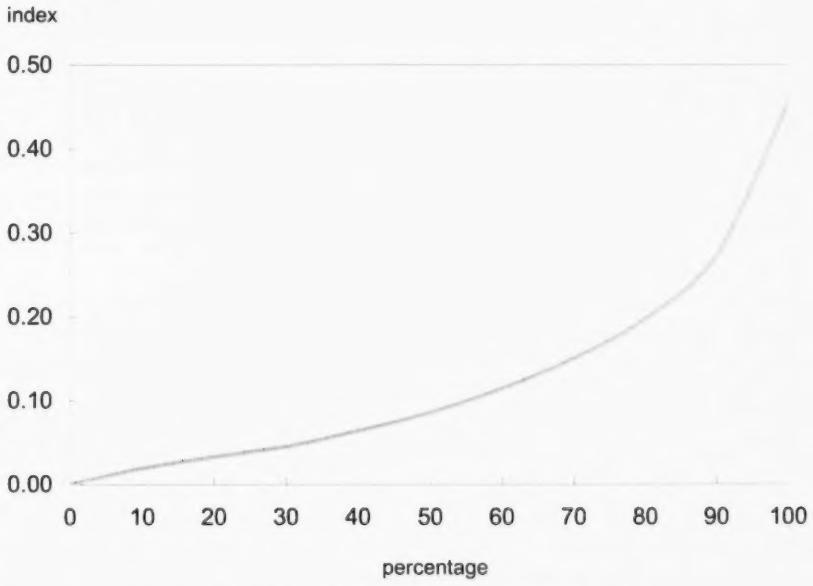
In order to create severity classes, the distribution of the global severity score was examined. The distribution has been separated into deciles. The first decile corresponds to the 10% of children with activity limitation with the lowest scores. The second decile corresponds to the next 10% of children with activity limitation with the lowest scores, etc. The average score was calculated for each decile and a plot of this average score as a function of the decile was produced in Chart 4. As can be seen in Chart 4, no obvious cut-off points in the global severity score distribution exist. Several techniques were considered in order to create the severity classes. Because of the smoothness of the distribution in Chart 4 and because of the requirement to use a simple method for data users, an intuitive graphical method was used to determine the cut-off points.

Chart 4
Distribution of the global score for children aged 0 to 4, Participation and Activity Limitation Survey, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Chart 5
Distribution of the global score for children aged 5 to 14, Participation and Activity Limitation Survey, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

After discussion with some data users, it was decided that the severity scale for children 5 to14 would be separated into 4 severity classes, Class #1 being the less severe and Class #4 the most severe. The creation of the classes has been done in two steps.

In a first step, an attempt was made to identify a "natural cut-off point" in the scale. Although this is not obvious, one can note that the beginning of the distribution is fairly linear up to 50th or 60th percentiles and then, the slope starts to increase more and more rapidly. This cut-off point in the trend of the distribution seems to correspond to a score around 1/8. This particular score corresponds to the score of someone with the maximum score for one type of disability and no points for the other types. Many such cases were found in the sample. Of course, there is a number of ways to obtain a score of 1/8. Because of the particular interpretation of this point, the cut-off was chosen to be exactly 1/8. This cut-off creates two groups:

The "less severe" group:			SI_{5-14}	<	1/8
The "more severe" group:	1/8	≤	SI_{5-14}	≤	1

For example, someone with the maximum score for seeing ($S_{SEE} = 1$) but no other disability, falls into the "more severe" group. Anyone with the maximum severity score for one disability type will, therefore, automatically be assigned to the "more severe" group.

The second step was to separate each of the two groups into two subgroups. The most logical cut-off points to do this were half and twice the maximum score for one disability type (cut-offs of 1/16 and 1/4). The point 1/16 corresponds to someone who would have half the maximum number of points for one disability type and nothing else. The cut-off of 1/4 corresponds to someone with the maximum number of points for two disability types and nothing else. Therefore, respondents with a score smaller than 1/16 fall into Class #1, those with a score between 1/16 and 1/8 fall in Class #2. Those with a score between 1/8 and 1/4 fall in Class #3 while those with a score larger than 1/4 fall in Class #4.

Class 1:			SI_{5-14}	<	1/16
Class 2:	1/16	≤	SI_{5-14}	<	1/8
Class 3:	1/8	≤	SI_{5-14}	<	1/4
Class 4:	1/4	≤	SI_{5-14}	≤	1

This type of classification has the advantage of being easy to understand and interpret by all users. Because of the subjective aspect of this classification, it is desirable not using specific terms in order to avoid misinterpretation. The classes are relative to each other, that is Class #1 is less severe than Class #2, which is less severe than Class #3, which in turns is less severe than Class #4. However, a nomenclature has been assigned to those classes for practical purposes. The terms "mild", "moderate", "severe" and "very severe" are used to refer to classes 1 to 4.

For children 0 to 4, a similar approach was used. It was decided that the severity scale for children 0 to 4 would be separated into two severity classes rather than four. Since there are four disability types for that group, the cut-off is 1/4:

Class 1:			SI_{0-4}	<	1/4
Class 2:	1/4	≤	SI_{0-4}	<	1

The terms "mild to moderate" and "severe to very severe" are used to refer to classes 1 and 2.

Appendix C: False positives in the 2006 Participation Activity Limitation Survey

As a new module for the 2006 PALS, the false positive module marked a new direction in the analysis of respondents to a post-censal activity limitation survey. The 2001 PALS found that approximately 25% of respondents who had indicated a limitation on the Census and were selected for PALS did not have a limitation according to the subsequent PALS interview. This attrition of the 2001 PALS sample prompted numerous questions concerning the characteristics of this group and why there is inconsistency in their reporting of activity limitations. There are several interesting characteristics of the false positive population that are discussed in this appendix, including age groups and proxy effects.

Age groups

Previous surveys on activity limitations have found a strong association between age and the prevalence of activity limitation. Similarly, there is also a strong association between the false positive rate and age, although the direction of this relationship changes with the age groups.

The most difficult age group in which to identify activity limitations is children age 0 to 4. The 2006 PALS surveys found that 61.8% of children 0 to 4 for whom a limitation was indicated on the Census and were selected for PALS did not have any limitation according to the definition of disability used by PALS. The rapid development of children within this age group typically leads to the misidentification of minor delays as limitations or disabilities.

The false positive rate drops sharply beyond the 0 to 4 age group to approximately 30% for children 5 to14 followed by a relatively steady decrease to 11.2% in 2006 for the 75 and over age group. There are, however, two interesting points to note on this declining trend. First, there is a considerable jump in the false positive rates for the 15 to 24 age group followed by a return to the steady decline. This age group marks the transition between the adult and children's versions of the questionnaires yet everyone receives the same filter questions on the Census. Thus, we are looking at the merging point of the adult and children's PALS populations and should expect some variation.

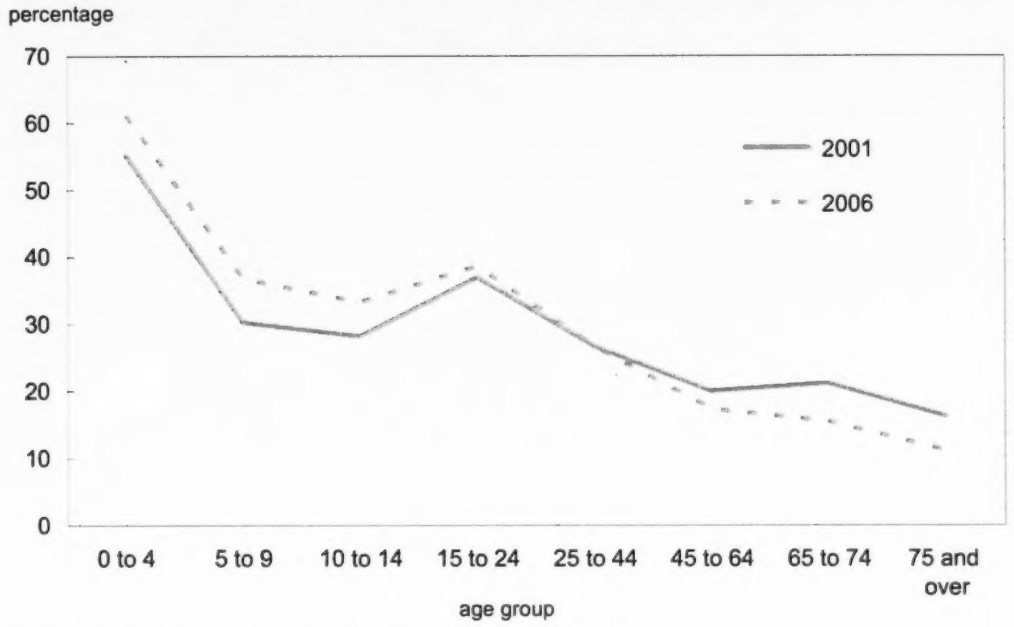
The second interesting pattern observed in the 2006 false positive rate is a dramatic shift in the distribution of the false positives. There is a considerable increase in the false positive rate for the 0 to 4 age group between 2001 and 2006, increasing 6.6 percentage points during the 5 year period from 55.2% to 61.2% in 2006. This gap slowly narrows as the age groups increase until the false positive rates for 2001 and 2006 are identical at 26.7% for the 25 to 44 age group. The opposite relationship becomes evident at the other end of the age spectrum where the false positive rate drops 5.1 percentage points from 16.3% to 11.2% between 2001 and 2006 (see Chart 6).

Proxy effects

Defining disability is a very difficult task for a single person. This task becomes doubly difficult when comparing the definitions of disability between two people, particularly when the two people are trying to agree on whether one of them has a disability. The person without a disability may find it easier to label someone else as having a disability compared to labeling themselves as having a disability. Following this stream of analysis, there are some interesting proxy effects in the false positive population concerning the identification of activity limitations and reasons for someone being a false positive. It should also be noted that this discussion of proxy and non-proxy effects relates to the adult population only.

The first notable difference between the proxy and non-proxy false positive populations is the 5.8 percentage point difference between the false positive rate for proxy interviews (13.6%) compared to the non-proxy interviews (19.6%). Given that much of the Census is completed by proxy, the lower false positive rate for proxy interviews in PALS suggests that there is more consistency when one or more proxies are identifying a limitation in a third person versus a proxy and a person with a mild limitation trying to agree if this limitation is sufficiently serious to be reported on a survey.

Chart 6
False positive rate, by age group, Participation and Activity Limitation Survey, 2001 and 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Further evidence of the inconsistency in the reporting of activity limitations between proxy and non-proxy respondents is found through an analysis of the reasons why the respondent became a false positive. The clearest evidence of this inconsistency is found by examining the proxy status and data on who completed the household's Census form for respondents who indicated that their inclusion in PALS was an error.

In cases where the target respondent had completed the Census form for their household, only 33.7% of PALS proxy interviews indicated the respondents inclusion in PALS was an error compared to 54.3% of PALS respondents who completed the PALS interview themselves. Previous PALS research has found that people with mild or cyclical limitations may report a limitation to the disability filter questions found on the Census and many other instruments on occasions when they are having a difficult time but will recover relatively quickly. Therefore, the discrepancy between the false positive rates for people who completed their own Census form but believe their inclusion in PALS was an error is likely attributable to the varying perception of the respondent's mild or cyclical limitation between the proxy and non-proxy participants. In addition, subsequent internal data capture quality assessments have revealed extremely low rates of errors, far below the error rate required to support the claims that participation in PALS was an error, indicating that participation in PALS was not a processing error on the part of the Census or PALS.

Table 13

Proxy rates and census form completion for respondents who believe their inclusion in Participation and Activity Limitation Survey was an error, PALS 2006

Who completed the census form for the household	Proxy status	
	Proxy	Non-Proxy
	percentage	
Respondent completed census or participated	33.7	54.3
Respondent did not participate in census form completion	66.3	45.7

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.